

# **Policy/Funding Group**

## **Overall System for Deaf/HH Children Birth-5**

### **System Goals**

#### **I. Identification**

- a. To identify Deaf/HH children ages 0-5 as early as possible.
- b. To provide a single point of entry and easy transition from screening to diagnostic audiology.

### **System Elements**

#### **a. Newborn Hearing Screening**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- No state statute, but there is Medicaid rule.
- Working on electronic submission of reporting.

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

#### **b. Transition to Re-screen**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- Large number of infants do not return to the hospital within the usual 3 week period for re-screening.
- Reasons parents may not return for re-screening:  
Transportation, religious issues, insurance coverage, moving, quality of initial screener (perhaps not motivating parents to return), emotional rejection of diagnosis (emotional support for parents required).
- Don't put burden for re-screening on parents, professionals should go to family's home to re-screen.
- People who are screened but then don't receive services (refer to policy and funding issues)

**2) What needs to happen to put this in place?**

- GBYS assist parents in returning for additional screening (HIPAA issues not overcome here yet).
- Make referral after first screening failure? Don't wait for re-screen?
- Prenatal care policy? Education on choice to begin with prenatal treatment? Require all doctors to recertify in areas that include hearing screening, etc.

- Michigan Care Improvement Registry (MCIR)- immunizations, re-screen, referrals
- Social workers to follow-up with parents? E.g. tie to WIC?

### **3) Who needs to be involved? What agencies/programs need to be involved?**

- Whose responsibility is it to transition parents to re-screen? Hospital? Primary care provider? Medical home?
- Policy must cover broad range of health care providers (EPSDT – Medicaid)
- Too many involved in the policy invites miscommunication. Also, many of these care providers and social services areas are already overwhelmed.
- Hospital to provide the follow-up when child fails the initial hearing screening there. Develop protocol for hospitals to follow-up when screening is failed.
- Midwives, rural birthing practices, volunteer screeners – how would follow-up occur? Train 6 regional specialists?

#### **c. Re-screen**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

#### **d. Transition from re-screen to diagnostic evaluation**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- Breakdown between screening and diagnosis (mandate?) – again, policy and funding issues

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

#### **e. Diagnostic Evaluation**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- Qualifications of the evaluator are a barrier.
- There are very few pediatric audiologists.
- Policies need to be in place to address training/education.
- Professional development.
- Good providers understand the families with whom they work.
- Medical model bias a barrier (communication of information of screening results to parents/family).
- How does the cultural model fit into the diagnostic evaluation?
- First barrier is in getting the child to the diagnostic evaluation – then can introduce communication options.
- Michigan geography/rural culture and resources a barrier.

- Ear/nose/throat doctor involved in diagnosis (reason why medical model and diagnosis is essential)
- The assessments of hearing loss should be done by qualified pediatric audiologists. There is a need for training to bring some audiologists from rural areas, such as the U.P. up to the standard. This should be mandatory.

**2) What needs to happen to put this in place?**

- Are we developing statewide mandates, or local district guidelines and recommendations?

**3) Who needs to be involved? What agencies/programs need to be involved?**

- Policy will be put in place by many departments, and funding levels will determine mandates vs guidelines, as well as input from the Stakeholders and Advisory Committees.

**f. Referral/Transition to Service Coordination**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- Some parents use private resources to begin education/treatment of their child, therefore they fall out of our system.
- System failure or failure to return due to parental choice? Is it a record keeping problem (returns not documented? Records not updated?)
- Training and follow-up are issues, as are parental concerns

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

**g. Periodic hearing screening throughout childhood**

- i. Monitoring risk factors for progressive/late onset hearing loss

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

**h. Awareness**

- i. Public
- ii. Parents
- iii. Professionals

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- Public awareness issues

**2) What needs to happen to put this in place?**

- Universally used, widely publicized point of entry (common knowledge for referral). Develop a system that everyone knows and will use.

**3) Who needs to be involved? What agencies/programs need to be involved?**

**i. Data file begins with EHDI**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

**j. Procedural Safeguards/Family Rights**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

**k. Mandatory Reporting**

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- New legislation has mandatory reporting requirements

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

## **II. Service or Care Coordination**

- a. To provide a seamless system of service delivery.
- b. Family access to key individuals at the beginning of identification to ensure uniform information provision.
- c. To provide a coordination of resources across agencies.

### **System Elements:**

- a. Coordinate communication between agencies
- b. Provide parents unbiased information on services.
- c. Access to unbiased information about communication options
- d. Review Eligibility determinations across agencies and funding issues
- e. Help to navigate transitions
- f. Links to appropriate services and qualified service providers
- g. Procedural Safeguards/Family Rights
- h. Single point of entry into system

### **1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- Early On 9 month program – Spring babies get services in Sept-October.
- If using EO as point of entry is a barrier
- The service coordinators for infants with hearing loss should be audiologists, speech and language pathologists, and teachers with endorsements in both early childhood and hearing impairment. These should be the professionals working with these children with hearing loss in their respective areas of specialization. This should be mandatory. Additionally, there should be mandatory training required of these professionals as to assessments of infants with hearing loss, working with the parents and infants in a natural family environment, providing information to the parents as to the hearing loss, modes of communication, hearing aids, how they can best work with their child, resources, including funding sources for hearing aids, and the rights of the parents. The training of these professionals should include auditory verbal therapy as well as how best to provide sign language instruction to the parents and infants, where the parents want sign language for their child.

### **2) What needs to happen to put this in place?**

- Single point of entry (as per New Mexico model – similar to Colorado's)
- Everyone agreed that a single point of entry into Early On/Special Education was essential.
- Funding from the state of Michigan will be essential.
- There should be a statewide coordinator. Somebody has to be in charge to make the necessary changes to improve the system.

### **3) Who needs to be involved? What agencies/programs need to be involved?**

- Michigan has special education services Birth-3 and EO services Birth-3: difficult to navigate dual system.
- Department of Education birth to 3; 11 children listed in special education under hearing impairment (i.e. given on IEP for special education; get minimum of 2 hrs)
- Data for EO – 2004: 45 enrolled. Part B – special education 30 school days.
- Part C Special education; 45 days for an IFSP (Individualized Family Services Plan) to be developed within summer or not.
- Need parent infant advisors who visit young people with special needs (masters, 3 yrs experience)
  - Topics which should be covered are Communication choices, Brain development, critical development, hearing aids and CI, minimize back noise, literacy, takes time to disseminate, obligation of school district to provide free and appropriate education.
- 45 days for initial IFSP meeting, then an additional 30 days to begin services.
- Lack of qualified service providers.
- Services should start immediately at referral.
- Connection with parent-infant person
- Assessment
- Home visits
- Case coordination
- Ski-Hi is 2 year service program
- Ontario, Texas, Colorado, Utah have a Parent-infant program funding provided by Community Health and Education
- Single point of entry, services by highly qualified people

### **III. Eligibility Determination**

- a. To determine eligibility in a timely manner.

#### System Elements:

- a. CSHCS
- b. Medicaid
- c. MICHILD
- d. Private insurances
- e. Early On
- f. Special Education
- g. Healthy Kids
- h. SSI
- i. Procedural Safeguards/Family Rights

#### **1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

- Communication between the systems; federal rules impact the cooperation between systems

#### **2) What needs to happen to put this in place?**

#### **3) Who needs to be involved? What agencies/programs need to be involved?**

- Eligibility for special education: resource room, teacher consultant, audiological evaluation, teacher order/assessment, H.I. provides educational impact, language and literacy an issue.
- Kristi Yashinaga-Itano: research to parents
- Issue: we live in a decentralized state; any system must be used across the State Of Michigan distinction between audiologists and educational audiologists
- DVD – how to communicate sensitive information – Oakland County
- In some places, joint IEP and IFSP – funding and services provided through both places
- Other places where services do not travel together if have some of the teacher consultants; need to understand deaf education and child development
- Regional coordinators but do not want to duplicate services
- Need centralized leadership

#### **IV. Plan Development**

- a. Family and child-centered services which identify and respect the family choices.
- b. To provide a choice of services that is specific to the needs, capabilities, and decisions of the child and family.

##### System Elements:

- a. Needs/Service Assessment
- b. Gather information on child's needs and development.
- c. Families concerns, priorities, and resources.
- d. The full range of services that will be utilized by the child and family.
- e. Develop language/communication plan.
- f. Procedural Safeguards/Family Rights

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**

- Communication among and between providers from identification through medical, educational, and community support agency intervention.

EHDI:

Sets policy for this communication?

Acts as facilitator for communication?

Provides framework for communication?



## **V. Services**

- a. To provide access to high quality services so that the family and child will reach their full potential.
- b. Qualified pediatric service providers.

System Elements:

### **Formal Services**

- a. Audiology
- b. Speech-Language Pathology
- c. Consultants
  - i. Hearing Impaired
  - ii. Teacher Consultant
- d. Sign Instructors/Interpreters**
  - Instructors need to be certified (American Sign Language Teachers Association–ASLTA) and should be separated from the field of interpreters, for these are two completely different fields, each with its own discrete characteristics. By the way, interpreters also need to be certified: QA II, QA III, or any national certifications. There are too many people who pretend to be interpreters even though they can barely sign. We need to ensure that professionals working with families with children who are deaf/hard of hearing are qualified.
- e. Medical Home/PCP**
  - i. Communication with the medical home
  - ii. Medical home identified as the primary care physician
- We need to clarify that all physicians are to refer all children who are deaf/hard of hearing to the agency (the single point entry).
  - f. Specialty referrals for children identified with hearing loss to otolaryngology, genetics, ophthalmology, and others as needed
  - g. Assistive Technology
  - h. Teacher/Early Interventionist
- j. Other**
  - i. Counseling
- This service is very important! It must be mandated to all families with children who are deaf/hard of hearing, not as an option for the families.
  - ii. Social worker
  - iii.

### **Informal Services**

- a. Role Model/Mentors
- b. Parent-to-Parent Support
- c. Support Groups
- d. Support Organizations

- 1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**
- 2) What needs to happen to put this in place?**
- 3) Who needs to be involved? What agencies/programs need to be involved?**

- Currently, there are not enough organizations devoted to parents/families of children who are deaf/hard of hearing. We may need to implement such a program.

## **VI. Quality Assurance/System Evaluation/Accountability**

### **a. Monitoring of outcomes serves as a basis for service planning and review**

- We need to decide on specific assessment tools to keep our assessment procedure standardized. Also, we need to include all factors of linguistic development, such as sign language (ASLPI: American Sign Language Proficiency Interview, a tool developed by a team of researchers in Gallaudet University, Washington, DC), auditory discrimination skills, speech skills, etc.

### **b. Integrated data system**

- There needs to be an agency that would monitor this process and gather all data (perhaps the same one that services as the single point entry agency).
  - c. Establishment of joint system outcomes
  - d. Joint/Aligned Policy

#### **System Elements:**

- a. Evidence-based joint system outcomes
- b. Monitoring of outcomes serves as a basis for service planning
- c. Evidence-based monitoring of progress
- d. Monitor, review child's progress over time
- e. Implement IFSP, monitor, review and conduct six month review
- f. Procedural Safeguards/Family Rights
- g. "Specialization" of service providers
- h. IEP birth to 5
- i. Tracking database for outcome measures
- j. We need to develop a "back-up" plan for the families whose children are not making sufficient progress. We already have too many children who are suffering from delayed linguistic development because of failure in implementing a back-up plan or revising the original language plan. We need to clarify that whenever the child is not making adequate progress, we MUST REVISE THE LANGUAGE PLAN.

**1) Are there problems/issues that are prohibiting us from reaching our vision and goals?**

**2) What needs to happen to put this in place?**

**3) Who needs to be involved? What agencies/programs need to be involved?**